

## **Ethics in Patient Care**

**Summary:** A conceptual program of research to explore how clinicians' should handle several unaddressed ethical dilemmas

**Section:** Ethics and Health Policy – Unit on  
Bedside Ethics

**Principal Investigator:** Marion Danis, M.D.

**Collaborators:**

Bioethics	Agnieszka Jaworska, Ph.D. Mark Parascandola, Ph.D. Jennifer Hawkins, Ph.D. Avi Astor, pre-doctoral fellow Gopal Sreenivasan, Ph.D.
Other NIH Researchers	None
Non-NIH Researchers	Risa Lavizzo-Mourey, M.D. Project on Death in America subcommittee members

**Background:**

While much debate has surrounded the use of principles in bioethics, concepts of respect for patient autonomy and the need to attend to concern for justice have been considered core concepts in clinical ethics. We have focused in this project on several aspects of these core ethical concepts that remain practically and theoretically troubling. The common thread in these analyses is the search to establish ways of adhering to core ethical concerns in non-ideal circumstances. In particular, with regard to concern for autonomy, how should clinicians address patients' wishes when they seem to still hold personal values but are personally no longer capable of acting upon them; how should clinicians respect patient wishes when it is uncertain what is best for them; and how should clinicians make use of communication strategies to negotiate decisions when clinicians and patients of different cultures bring diverse expectations and goals in the face of illness. With regard to concern for justice, how should the clinician act on the obligation to provide access to care in the absence of universal health insurance in an imperfect world where it is unclear to what extent others will act on this obligation?

A second focus of this project has been the translation of ethical analyses into ethics curriculum material. While there has been a remarkable effort to conceptually and empirically explore the practical ramifications of ethical concepts and principles in bioethics, there has been a lag in translating these empirical findings into recommendations for clinical practice. Hence, a part of this project is designed to translate conceptual arguments and empirical findings into useful curricular materials.

**Objectives:**

This research aims to further the conceptual analysis of and promote skills of clinicians for handling these ethical dilemmas, by focusing on the following objectives:

1. To analyze how clinicians ought to approach key ethical concerns of autonomy, diversity, and justice under a variety of non-ideal circumstances
2. To suggest strategies for educating clinicians about the resolution of ethical dilemmas

**Methods:**

This program of research involves review of existing ethics literature and explores new avenues of analysis for the dilemmas of interest. In addition to ethical analyses, we have conducted critical literature reviews and developed consensus statements. The critical literature reviews entailed systematic reviews of all articles found through Medline searches to assess the validity of their conclusions. Consensus development involved the modified use of the elements of the nominal group process. First, group participants list their ideas with comment from others, then a group discussion of the listed ideas is conducted to clarify and evaluate them. The ideas are then organized to inform a draft statement. The draft statement is then criticized and revised multiple times.

**Results:****1. Analysis of approaches to key ethical concerns in non-ideal circumstances****a. Autonomy**

During her tenure as a fellow in the Department of Clinical Bioethics, working with Marion Danis as her mentor, Agnieszka Jaworska addressed the question: Should we, in efforts to best respect a patient with dementia, give priority to the preferences of and attitudes she held before becoming demented, or should we follow her present preferences? <sup>1</sup>

Jaworska's analysis contrasts with the two leading views on how such dilemmas should be handled. One prominent view, represented by Dresser is that decisions on behalf of a demented person should address the person's interests at the time of the decision. The reasoning here is that attending to wishes that the person no longer holds, does her no good. The person with prior wishes is not necessarily the same person as the one currently at hand. The alternative view espoused by Dworkin is that one should follow the demented person's previously expressed wishes and values. In his view we are not taking the demented individual's autonomy and well-being seriously if we don't follow wishes expressed when her autonomous capacity was intact.

Jaworska argues that the current interests of the demented patient should be taken seriously. In recommending adherence to a demented patient's current wishes, she sides with Dresser but uses different reasoning. She suggests that

many demented patients, at least early on in the dementing process, may still be capable of autonomy and may still have authority regarding their well-being. But, unlike Dworkin who bases autonomy on decision-making capacity, Jaworska associates autonomy predominantly with the capacity to value and she associates well-being with living in accordance with one's values. Therefore, adherence to current values is both respectful of the person's autonomy and well-being. To act accordingly involves the facilitation of decisions and actions that the person may no longer be capable of herself, but which serve her autonomy and well-being. Thus, for example, if a patient previously had been financially prudent and had avoided frivolous expenditures, but now, as she becomes demented, wishes to find pleasure in and wants to purchase more frivolous things, it may be respectful of her personhood to facilitate the decision to purchase items she currently wants. Similarly, consider a patient who had previously expressed wishes to have life sustaining treatments while his wife was alive and he shared certain religious views with her. Subsequently he loses his wife and develops early signs of dementia. He now expresses a desire to forgo aggressive treatments because he doesn't see the point anymore. If, on careful assessment this wish is not the result of transient depression and seems to be a strongly held view, it may be worthy of adherence.

In a second analysis, related to concern for autonomy, Parascandola, Hawkins and Danis have explored how the lack of certainty in medical practice should be handled in the course of efforts to respect patient autonomy. The current norm in medical practice entails shared decision-making between physician and patient. The physician must convey to the patient the relevant information needed to make medical decisions, yet the situation at hand is often riddled with uncertainty regarding matters such as the likelihood of a diagnosis, the likelihood of success with a treatment intervention, the probability of side effects from an intervention, the prognosis in the face of illness. Hence the clinician may find communication in the face of such uncertainty more difficult and consequently be more reticent to be frank with the patient. We argue that hesitation about informing the patient in the face of uncertainty is problematic. The clinician should be all the more vigilant about conveying the situation to the patient because the patient has a strong interest in knowing the circumstances regardless of how difficult it may be to explain it. In making this argument we address the view offered by critics, such as Carl Schneider, who considers the endorsement of respect for patient autonomy as excessive, or what he calls 'mandatory autonomism' - a shift from merely allowing patients to participate in decision-making to more aggressively forcing patients to do so. We confront this criticism by arguing that respect for autonomy is a large project that entails more than merely informing patients for the sake of involving them in decisions. Rather, it needs to be seen as an effort to respect persons more broadly and as such the provision of information to patients is not merely an instrumental act meant to facilitate their decision-making capacity. Rather, offering information serves to respect the fact that persons may wish to fully understand their situations in all its complexity regardless of whether they wish to make decisions

for themselves. On this view, the clinician cannot know all that matters to the patient or the ramification of information regarding these matters, and hence does well to discuss information explicitly with the patient.

b. Beneficence and justice

Work that is more recent has focused on the principle of beneficence and strategies for adhering to it under circumstances of imperfect justice. In particular, Avi Astor has worked as a fellow with Marion Danis and Gopal Sreenivasan to analyze the obligation of physicians to give medical care to patients who lack health insurance and thus cannot pay for much of their care. Offering free care is an important way to meet the health care needs of the uninsured in a health care system that does not offer universal health insurance. While several professional organizations, such as the AMA and the American Board of Internal Medicine, endorse the provision of free care by physicians, and several programs are designed to promote community wide efforts to facilitate physician volunteerism, there has been little analysis of how much free care physicians should give. Astor, Sreenivasan, and Danis have outlined a principle of fair beneficence that offers practical guidance about how much free care to offer. The concept of beneficence entails promoting the welfare of others. Providing free care to those who cannot pay is such a beneficent act. Using the notion of fair beneficence, we conceive of beneficence as a collective endeavor in which each individual is responsible for contributing his or her fair share of beneficence. This notion serves to address the problem that not everyone does their part; fair beneficence obliges each individual to contribute his or her share, but no more, to help others. It thus distributes the obligation to promote the welfare of the needy equitably. We translate this concept of fair beneficence into practical terms by establishing what a clinician's fair share is. We estimate the cost of providing primary care for all the uninsured based on current actuarial costs per capita for primary care in the managed care setting, and distribute this cost among all primary care physicians in the U.S. Based on this estimate, we extrapolate that if all primary care physicians made a modest contribution toward free care of the uninsured in the US, this might significantly increase access to primary care for the uninsured.

2. To suggest strategies for educating clinicians about the resolution of ethical dilemmas encountered in practice

Several publications under the rubric of this program of research have focused on translating conceptual and empirical work in bioethics into practice. This work has been sponsored by the Robert Wood Johnson Foundation initiative, Promoting Excellence in End-of-Life Care, and the Open Society Project on Death in America as part of the immense effort in the US over the last decade to improve the care of dying patients. The focus of efforts in this project has been related to longstanding work of the PI while serving as chair of the Ethics Committee of the Society of Critical Care Medicine. Two major themes in the publications stemming from this project are summarized here.

The first theme is that in providing care to dying patients in the ICU setting, it is crucial to avoid allowing the available technology to dictate the plan of care. Rather it is essential to explore with patients and their families what can be realistically achieved and how the patient's values and preferences might be melded with this reality to develop a plan of care at the end of life that is feasible and respectful of the patient.

The second key theme emphasizes the influences of ethnicity, religion, and socio-economic status on patients' experiences and preferences about terminal illness. It is crucial to bear in mind that individuals may feel a sense of identification with any number groups, the degree of affiliation with a culture may vary from person to person, and that group affiliation may have little predictive value regarding a given individual's views. It is therefore important, even in the face of knowing about ethnic differences, to avoid stereotyping individuals. Thus, while it is important to understand an individual's background, clinicians are likely to provide the best care by being respectful of the particular views and needs of each individual patient.

### **Future directions:**

Future analyses will focus on findings from our empirical studies of how physicians handle ethical dilemmas. These studies reveal that clinicians handle the majority of ethical dilemmas they encounter without seeking ethical advice. In internists' narratives about the ways they resolve these dilemmas, we have found that they report efforts to avoid conflict, which can at times override other values such as respecting a patient's stated choices. The implications of such a strategy are ethically interesting and important to consider.

Why clinicians hesitate to use ethics consultation also warrants analysis. Many physicians report that ethical dilemmas concerning distributive justice are rarely brought to the attention of ethics consultants. Many non-physicians mention hesitancy to use consultation because of fear of reprisal. Such hesitations seem troubling and warrant analysis and a search for strategies to overcome them.

### **Publications**

1. Jaworska A, Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value, *Philosophy and Public Affairs*, Vol. 28:105-138.
2. Parascandola M, Hawkins J, Danis M. Patient Autonomy and the Challenge of Clinical Uncertainty. *Kennedy Institute of Ethics Journal* 2002 (in press).
3. Danis M. Improving end-of-life care in the intensive care unit: what's to be learned from outcomes research? *New Horiz.* 1998;6: 110-118.

4. Danis M, Federman D, Fins J, et al. Incorporating palliative care into critical care education: Principle, challenges, and opportunities. *Critical Care Medicine* 1999;27:2005-2013.
5. Danis M. Role of Ethnicity, Race, Religion, and Socio-economic Status in End of Life Care in the ICU in *The Transition From Cure to Comfort: Managing Death in the Intensive Care Unit*. Curtis JR and Rubenfeld GD, Eds. Oxford University Press, Oxford 2000
6. The Ethics Committee of the Society of Critical Care Medicine. Recommendations for end-of-life care in the intensive care unit. Critical Care Medicine 2001;29:2332-2348.
7. Danis M and Lavizzo-Mourey R. Respecting diversity in geriatric palliative care in *Geriatric Palliative Care*. Meier D and Morrison S, Eds. Oxford University Press, (in press)